

2018 Current Fiscal Year Report: Interagency Autism Coordinating Committee

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1. Department or Agency

Department of Health and Human Services

2. Fiscal Year

2018

3. Committee or Subcommittee

Interagency Autism Coordinating Committee

3b. GSA Committee No.

31970

4. Is this New During Fiscal Year?

No

5. Current Charter

09/30/2018

6. Expected Renewal Date

09/30/2020

7. Expected Term Date

8a. Was Terminated During Fiscal Year?

No

8b. Specific Termination Authority

42 USC 280i-2

8c. Actual Term Date

9. Agency Recommendation for Next Fiscal Year

Continue

10a. Legislation Req to Terminate?

Not Applicable

10b. Legislation Pending?

Not Applicable

11. Establishment Authority

Statutory (Congress Created)

12. Specific Establishment Authority

42 USC 280i-2

13. Effective Date

12/19/2006

14. Committee Type

Continuing

14c. Presidential?

No

15. Description of Committee

Scientific Technical Program Advisory Board

16a. Total Number of Reports

1

16b. Report Date

10/01/2017

Report Title

2016-2017 Strategic Plan

Number of Committee Reports Listed: 1

17a. Open 3 17b. Closed 0 17c. Partially Closed 0 Other Activities 0 17d. Total 3

Meetings and Dates

Purpose

To discuss committee business, updates, and issues related to ASD and services activities.

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Start

10/24/2017 - 10/24/2017

01/17/2018 - 01/17/2018

04/19/2018 - 04/19/2018

End

Number of Committee Meetings Listed: 3

	Current FY	Next FY
18a(1). Personnel Pmts to Non-Federal Members	\$12,000.00	\$19,200.00
18a(2). Personnel Pmts to Federal Members	\$0.00	\$0.00
18a(3). Personnel Pmts to Federal Staff	\$751,812.00	\$766,848.00
18a(4). Personnel Pmts to Non-Member Consultants	\$0.00	\$0.00
18b(1). Travel and Per Diem to Non-Federal Members	\$34,289.00	\$34,975.00
18b(2). Travel and Per Diem to Federal Members	\$0.00	\$0.00
18b(3). Travel and Per Diem to Federal Staff	\$42,803.00	\$43,659.00

18b(4). Travel and Per Diem to Non-member Consultants	\$0.00	\$0.00
18c. Other(rents,user charges, graphics, printing, mail, etc.)	\$1,003,593.00	\$1,106,709.00
18d. Total	\$1,844,497.00	\$1,971,391.00
19. Federal Staff Support Years (FTE)	5.80	6.00

20a. How does the Committee accomplish its purpose?

The Interagency Autism Coordinating Committee (IACC) was established in August 2007 as required by the Combating Autism Act (CAA) of 2006 (P.L. 109-416) to coordinate all efforts within the Department of Health and Human Services (HHS) concerning autism spectrum disorder (ASD). The committee was reauthorized by the Combating Autism Reauthorization Act of 2011 (CARA) (P.L. 112-32), enacted on September 30, 2011 and again by the Autism Collaboration Accountability Research Education and Services (CARES) Act, enacted on August 8, 2014. New public and federal members were appointed to the IACC in November 2015. The IACC's charge (under the Autism CARES Act) is to: (1) develop and annually update a summary of advances in ASD research related to causes, prevention, treatment, early screening, diagnosis or ruling out a diagnosis; intervention, and access to services and supports for individuals with ASD; (2) monitor autism spectrum disorder research, and to the extent practicable services and support activities, across all relevant Federal departments and agencies, including coordination of Federal activities with respect to autism spectrum disorder; (3) make recommendations to the Secretary regarding any appropriate changes to such activities, including recommendations to the Director of NIH with respect to the strategic plan; (4) make recommendations to the Secretary regarding public participation in decisions relating to ASD; (5) develop a strategic plan for the conduct of, and support for, autism spectrum disorder research, including as practicable for services and supports, for individuals with an autism spectrum disorder and the families of such individuals, which shall include—(A) proposed budgetary requirements; and (B) recommendations to ensure that autism spectrum disorder research, and services and support activities to the extent practicable, of the Department of Health and Human Services and of other Federal departments and agencies are not unnecessarily duplicative; and (7) submit to the Congress and the President the annual update of the summary of advances; and (8) the strategic plan and annual updates to the strategic plan. The IACC successfully finalized their first annual Strategic Plan for ASD Research in January 2009, and issued updated Strategic Plans in 2010 and 2011, which were delivered to Congress, the Secretary, and the Director of NIH. The IACC also issued Strategic Plan Updates in 2012 and 2013 and were delivered to the HHS Secretary and Congress. In October 2017, the IACC issued the 2016-2017 IACC Strategic Plan for Autism Spectrum Disorder, which contains an entirely new set of 23 objectives that describe the top priority areas for autism research

and services based on their analysis of research progress and changes in services over the last several years. The IACC Strategic Plan and its subsequent updates have been produced through collaborative effort between the IACC, scientists, advocacy organizations, and the public to identify needs and opportunities for research, services and policy to improve the lives of individuals with autism spectrum disorder and their families. The plan cites specific objectives for different areas of ASD research and services, including diagnosis, biology of ASD, risk factors, treatments, services, lifespan issues, surveillance/infrastructure/workforce/outreach. In April 2018, the IACC compiled its annual Summary of Advances in ASD Research, describing the top 20 ASD research advances identified by the committee from research articles published in CY 2017. This publication identifies emerging discoveries that may be relevant to the update of the IACC Strategic Plan and other IACC activities, and will be published in FY-19. The Committee also continues to monitor Federal activities related to ASD through presentations at meetings of the full IACC and the Subcommittees and provide access to meeting webcasts, podcasts, minutes, transcripts and materials on the IACC website. All IACC meetings, including IACC conference calls and IACC-sponsored workshops, are open to the public.

20b. How does the Committee balance its membership?

The Interagency Autism Coordinating Committee is composed of 29 appointed members. Currently there are 12 public members and 17 Federal members. Three public members originally appointed have left the committee, leaving vacancies. The public membership is required to include at least two individuals with a diagnosis of Autism Spectrum Disorder (ASD) (the current committee includes two public members who are on the autism spectrum); at least two parents or legal guardians of an individual with ASD (the current committee includes five public members who are parents/guardians of individuals with a diagnosis of ASD); and at least two representatives of leading research, advocacy, and service organizations for individuals with ASD (current committee includes 12 public members who are leaders in advocacy, research and service organizations). The Federal members represent 13 Government agencies that serve individuals with ASD (NIH has 6 members representing different institutes and the Office of the Director).

20c. How frequent and relevant are the Committee Meetings?

The full committee held 3 meetings in FY 2018. All IACC meetings were open to the public and also available via videocast and/or a teleconference line. The committee also held 2 other activities in the form of a working group conference call and a workshop in September 2018. These were also open to the public.

20d. Why can't the advice or information this committee provides be obtained

elsewhere?

This committee is mandated by the Combating Autism Act of 2006 of the Public Health Service Act, as amended, and was reauthorized by the Autism Collaboration, Accountability, Research, Education and Support (CARES) Act of 2014. It coordinates efforts concerning autism spectrum disorder among member federal agencies and private autism research, service, and advocacy organizations. The Committee's primary mission is to provide advice to the Secretary of Health and Human Services on matters concerning autism spectrum disorder and to facilitate the efficient and effective exchange of information on autism activities among the member federal agencies in order to enhance coordination of autism-related programs and activities. The Committee, composed of federal officials and public stakeholders, assists in increasing public understanding of the member agencies' activities, programs, policies and research and serves as a public forum for discussions related to autism spectrum disorder. There are U.S. federal advisory committees that are focused on the needs of individuals with disabilities, but there is no other federal advisory committee that is dedicated specifically to the needs of individuals with autism spectrum disorder and that performs functions similar to the IACC.

20e. Why is it necessary to close and/or partially closed committee meetings?

All meetings of the IACC and its subcommittees were open to the public.

21. Remarks

The FY2018 costs for this ACR include the expenses directly related to the managing of the IACC but do not reflect all of the inter-related costs. The committee produced a new Summary of Advances in Autism Spectrum Disorder Research for CY 2017 and a new IACC Strategic Plan for 2016-2017 that was published in October 2017. These documents are not considered "Reports" but information created by the committee that is used by the Office of Autism Research Coordination, along with other information/sources, to report to Congress. Based on the assignment of duties, Dr. Susan Daniels serves as both the designated federal official and the committee decision maker for this committee. All members on the committee in FY-2018 have terms that will expire on 9/30/2019 except Dr. Joshua Gordon, who is the Chair. He will be reappointed to continue through 9/30/2019. Also Dr. James Battey retired and his end date has been changed to 6/1/2018. Dr. Gordon and Dr. Ronyak were missed in the 2017 report and were members of the committee in FY 17 and FY18. Aaron Bishop's term ended in FY17; his end date was not updated in the 2017 report. Costs: The IACC Committee had 3 meetings and held 1 workshop and 1 working group conference call. Federal staff were required to attend specific meetings dealing with autism and other issues related to this committee's function. Other Costs include expenses for printing, meeting facilities, supplies, special

mailing, contacts/contractor staff, video conferencing, and other communication costs.

Designated Federal Officer

Susan A. Daniels Director, Office of Autism Research Coordination

Committee Members	Start	End	Occupation	Member Designation
Amaral, David	01/11/2016	09/30/2019	Distinguished Professor	Special Government Employee (SGE) Member
BIANCHI, DIANA	01/12/2017	09/30/2019	DIRECTOR	Regular Government Employee (RGE) Member
Ball, James	09/20/2015	09/30/2019	President and CEO	Special Government Employee (SGE) Member
Battey, James	04/01/2015	06/01/2018	Director	Regular Government Employee (RGE) Member
Birnbaum, Linda	04/01/2015	09/30/2019	Director	Regular Government Employee (RGE) Member
Collins, Francis	04/01/2015	06/30/2019	Director	Regular Government Employee (RGE) Member
Crane, Samantha	10/04/2015	09/30/2019	Director of Public Policy	Special Government Employee (SGE) Member
Dawson, Geraldine	09/20/2015	09/30/2019	Professor	Special Government Employee (SGE) Member
Etzel, Ruth	01/11/2016	09/30/2019	Director	Regular Government Employee (RGE) Member
Farchione, Tiffany	04/01/2015	09/30/2019	Medical Officer	Regular Government Employee (RGE) Member
GORDON, JOSHUA	10/17/2016	09/30/2018	DIRECTOR	Regular Government Employee (RGE) Member
Harris, Melissa	04/01/2015	09/30/2019	Director	Regular Government Employee (RGE) Member
Kavanagh, Laura	04/01/2015	09/30/2019	Director	Regular Government Employee (RGE) Member
Koroshetz, Walter	04/01/2015	09/30/2019	Acting Director	Regular Government Employee (RGE) Member
Mandell, David	10/04/2015	09/30/2019	Associate Professor	Special Government Employee (SGE) Member
Pelphrey, Kevin	09/20/2015	09/30/2019	Harris Professor	Special Government Employee (SGE) Member
Pena, Edlyn	10/04/2015	09/30/2019	Associate Professor	Special Government Employee (SGE) Member
Pincock, Laura	01/12/2017	09/30/2019	Pharmacist Officer	Regular Government Employee (RGE) Member
RONYAK, MARCELLA	07/25/2017	09/30/2019	DEPUTY DIRECTOR	Regular Government Employee (RGE) Member
Reichardt, Louis	10/04/2015	09/30/2019	Director	Special Government Employee (SGE) Member
Ring, Robert	10/04/2015	09/30/2019	Founder and President	Special Government Employee (SGE) Member
Robison, John	09/20/2015	09/30/2019	Neurodiversity Scholar, Author, Self-Advocate	Special Government Employee (SGE) Member
Shapira, Stuart	07/08/2016	09/30/2019	Associate Director	Regular Government Employee (RGE) Member
Singer, Alison	09/20/2015	09/30/2019	Co-Founder and President	Special Government Employee (SGE) Member
Spencer, Melissa	04/04/2017	09/30/2019	Deputy Associate Commissioner	Regular Government Employee (RGE) Member

Taylor, Julie	09/20/2015 09/30/2019 Assistant Professor	Special Government Employee (SGE) Member
Wexler, Lawrence	04/01/2015 09/30/2019 Director	Regular Government Employee (RGE) Member
Williams, Nicole	10/25/2015 09/30/2019 Health Science Program Manager	Regular Government Employee (RGE) Member

Number of Committee Members Listed: 28

Narrative Description

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entirely new set of 23 objectives that describe the top priority areas for autism research and services based on their analysis of research progress and changes in services over the last several years. The IACC Strategic Plan and its subsequent updates have been produced through collaborative effort between the IACC, scientists, advocacy organizations, and the public to identify needs and opportunities for research, services and policy to improve the lives of individuals with autism spectrum disorder and their families. The plan cites specific objectives for different areas of ASD research and services, including diagnosis, biology of ASD, risk factors, treatments, services, lifespan issues, surveillance/infrastructure/workforce/outreach. In April 2018, the IACC issued its annual Summary of Advances in ASD Research, describing the top 20 ASD research advances identified by the committee from research articles published in 2017. This publication identifies emerging discoveries that may be relevant to the update of the IACC Strategic Plan and other IACC activities. The Committee also continues to monitor Federal activities related to ASD through presentations at meetings of the full IACC and the Subcommittees and provide access to meeting webcasts, podcasts, minutes, transcripts and materials on the IACC website. All IACC meetings, including IACC conference calls and IACC-sponsored workshops, are open to the public.

What are the most significant program outcomes associated with this committee?

Checked if Applies

- | | |
|---|-------------------------------------|
| Improvements to health or safety | <input checked="" type="checkbox"/> |
| Trust in government | <input checked="" type="checkbox"/> |
| Major policy changes | <input type="checkbox"/> |
| Advance in scientific research | <input checked="" type="checkbox"/> |
| Effective grant making | <input type="checkbox"/> |
| Improved service delivery | <input checked="" type="checkbox"/> |
| Increased customer satisfaction | <input checked="" type="checkbox"/> |
| Implementation of laws or regulatory requirements | <input checked="" type="checkbox"/> |
| Other | <input type="checkbox"/> |

Outcome Comments

NA

What are the cost savings associated with this committee?

Checked if Applies

- | | |
|-----------------------|-------------------------------------|
| None | <input type="checkbox"/> |
| Unable to Determine | <input checked="" type="checkbox"/> |
| Under \$100,000 | <input type="checkbox"/> |
| \$100,000 - \$500,000 | <input type="checkbox"/> |

\$500,001 - \$1,000,000
\$1,000,001 - \$5,000,000
\$5,000,001 - \$10,000,000
Over \$10,000,000
Cost Savings Other

☐
☐
☐
☐
☐

Cost Savings Comments

The committee's mission is to develop and annually update a strategic plan for the conduct of, and support for ASD research.

What is the approximate Number of recommendations produced by this committee for the life of the committee?

105

Number of Recommendations Comments

The 2016-2017 IACC Strategic Plan for Autism Spectrum Disorder contains 23 research objectives, each of which is a recommendation for a research priority. The 2011 IACC Strategic Plan for Autism Spectrum Disorder Research that has now been superseded by the 2016-2017 IACC Strategic Plan contains 23 research objectives, each of which is a recommendation for a research priority. The IACC also sent two advisory letters to the Secretary, DHHS, in 2011 and one advisory letter in 2013 (these letters each contain multiple recommendations, but for simplicity, they will be counted here as one recommendation per letter). In addition, at a meeting of the IACC, the committee recommended research on a particular issue which then was supported through an interagency effort. These 105 recommendations are the total number of recommendations for FY2008 through FY2018.

What is the approximate Percentage of these recommendations that have been or will be Fully implemented by the agency?

44%

% of Recommendations Fully Implemented Comments

Of the 105 recommendations (44%) have been fully implemented (including 45 Strategic Plan objectives and 1 research recommendation).

What is the approximate Percentage of these recommendations that have been or will be Partially implemented by the agency?

30%

% of Recommendations Partially Implemented Comments

Of the 105 overall recommendations made by the IACC to date, 33 or 31% have been partially implemented (including 31 Strategic Plan objectives and 2 letters to the Secretary). Together, 79 of the 105 recommendations (75%) have been either partially or fully implemented.

Does the agency provide the committee with feedback regarding actions taken to implement recommendations or advice offered?

Yes ☒ No ☐ Not Applicable ☐

Agency Feedback Comments

The agency provides feedback at the IACC meetings, in reports, in response letters, and on the agency web site.

What other actions has the agency taken as a result of the committee's advice or recommendation?

Checked if Applies

Reorganized Priorities	<input checked="" type="checkbox"/>
Reallocated resources	<input checked="" type="checkbox"/>
Issued new regulation	<input type="checkbox"/>
Proposed legislation	<input type="checkbox"/>
Approved grants or other payments	<input checked="" type="checkbox"/>
Other	<input type="checkbox"/>

Action Comments

In response to recommendations, Federal agencies have included consideration of objectives in the IACC Strategic Plan in their programmatic planning effort which has influenced research and policies, though in most cases the Strategic Plan was only one of many factors considered. In some cases, projects such as the funding of specific workshops, were prioritized by agencies largely, but not solely, in response to the IACC Strategic Plan. In addition, in some cases, initiatives were planned in response to IACC recommendations, which has resulted in grants being funded in areas that were not previously covered.

Is the Committee engaged in the review of applications for grants?

No

Grant Review Comments

NA

How is access provided to the information for the Committee's documentation?

Checked if Applies

Contact DFO	<input checked="" type="checkbox"/>
Online Agency Web Site	<input checked="" type="checkbox"/>
Online Committee Web Site	<input checked="" type="checkbox"/>
Online GSA FACA Web Site	<input checked="" type="checkbox"/>
Publications	<input checked="" type="checkbox"/>
Other	<input type="checkbox"/>

Access Comments

NA